# Additional 'Do No Harm' ethical considerations for research during COVID-19<sup>1</sup>



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<sup>&</sup>lt;sup>1</sup> The additional guidance in this document is adapted from: 'Safeguarding in International Development Research: Practical application of UKCDR Safeguarding Guidance during COVID-19' published by the UK Collaborative on Development Research (UKCDR).

Research during global health emergencies is vital as quality evidence can inform, improve and help to evaluate responses both in the short and long term. However, safeguarding, research ethics, data integrity and 'Do No Harm' principles should take on additional importance during the COVID-19 pandemic. It is also even more important to consider how the voices of different marginalised groups will be captured in research and data collection during this challenging time, noting the unique vulnerabilities and risks they face in this changing context [see box 1]. This guidance is to support you to undertake research during a global health emergency.

## Notes on terminology:

- The term 'enumerator' is used to refer to anyone collecting data and carrying out interviews (face-to-face or online).
- The term 'research' encapsulate everything from academic research to MEL data collection. Ethical standards apply to all types of data collection.

# Box 1: GESI concerns during COVID-19:

- Research demonstrates that women and marginalised groups are disproportionately
  impacted by COVID-19. Groups at the intersection of inequalities, for instance when
  gender inequality overlaps with other forms of exclusion including those related to age,
  class, disability, and sexual orientation, gender identity and expression, are at particular
  risk of adverse impacts from the COVID-19 crisis (SDDirect 2020).
- The impact ranges from greater risks of contracting the virus for some, including women and people with disabilities, to serious consequences in access to healthcare, food security, livelihoods, education and increases in violence and abuse, particularly towards women (SDDirect, 2020).
- Sexual exploitation, harassment and abuse is likely to increase, perpetrated by security & justice actors who are deployed to enforce lockdowns and by humanitarian actors (Spearing & Clugston, 2020) and an influx of aid workers who take advantage of lowered scrutiny and drastically reduced or overburdened public services (UKCDR, 2020).
- The move to digital services / data collection methods can further alienate women and girls in low-income countries who do not have access to a mobile phone or the internet (UN Women, 2020). There are similar risks for those living in rural areas, who have low literacy and have a disability.

When thinking about research ethics during a global health emergency, the following ethical principles need to be kept in mind:

- The dignity (and health and well-being) of individuals and groups must take priority above everything: During COVID-19 it is highly unethical to approach people to take part in research if their basic healthcare needs are not being addressed as part of the response effort.
  - a. Research should not be supported unless the basic health needs of research participants are being addressed through the response effort. Research funders

- need to work in partnerships with humanitarian organisations and ministries of health to ensure this.<sup>2</sup>
- b. In a time of increased stress and anxiety, will asking people to participate in research put them under further (and unnecessary) stress? Can the data collection components of the research be postponed?
- c. Can data collection ideas (e.g. remote) be discussed with a sample of participants to get their feedback on whether they feel it is fair and appropriate to go ahead?
- d. How can participants be compensated for their time / loss of earnings?
- e. With the suspension and closure of many services, how can it be ensured that referral systems are effective and that enumerators are confident that they can refer people to those who are responsible? How can it be ensured that participants know where and how to access health care and mental health support?
- f. Do consent procedures need to be revised because of pressure to produce rapid results or changes in research design to respond to rapidly changing contexts/issues? How can consent can be given that is fully informed, meaningful and freely given? Given the uncertainty during COVID-19, participants may feel more likely to believe that their access to resources could be depending on their participation in the research. As a result, they may feel they have to participate, even if they do not want.
- g. What measures can be taken to ensure the welfare (physical, mental and emotional) of researchers?
- h. In countries where authoritarianism is increasing as a result of enforcement of COVID-19 requirements, what additional measures need to be included to ensure the safety and security of enumerators and research participants (e.g. from increased risk of police brutality)?
- 2. Safeguarding and Protection<sup>3</sup>: During COVID-19 the potential risk of domestic violence, sexual exploitation, gender-based violence, and the neglect, abuse and exploitation of children and vulnerable adults increases. Online and digital methodologies pose a different set of safeguarding risks that need to be considered. A different set of skills, including strong communication skills, may be required of the data collectors and researchers.
  - a. How can it be ensured that everyone involved can access advice and support on protection and safeguarding concerns? Are there clear routes for contacting protection and safeguarding focal points or alternative appropriate trained contacts if the primary contact is not available?
  - b. What additional measures are being taken to identify any additional safeguarding risks and to mitigate against them?
  - c. With the suspension and closure of many services, how can any changes to referral points, mechanisms or services as a result of COVID-19 be identified and managed?
  - d. How can the effectiveness of reporting / investigation and disciplinary procedures be ensured?
  - e. Have the safeguarding risks of using online/remote technologies and platforms been identified?
  - f. Will participants have safe spaces to engage in (remote) data collection? Given that participants are likely to be at home with other family members, it may be

<sup>&</sup>lt;sup>2</sup> Nuffield Council on Bioethics. (2020) *Research in global health emergencies: ethical issues short report*, Available at: <a href="https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies/our-call-for-action">https://www.nuffieldbioethics.org/publications/research-in-global-health-emergencies/our-call-for-action</a>.

<sup>&</sup>lt;sup>3</sup> Note: In CA safeguarding is about the potential abuse that could arise from encountering CA representatives or our work; so domestic violence or other protection incidents in the community do not fall under safeguarding.

challenging to achieve any privacy and everything participants say, write, draw or photograph may be overseen or overheard by others.

- Risks assessments: Research during COVID-19 introduces new and heightened risks (and new Do No Harm considerations).
  - a. How can it be ensured that all research partners and participants are receiving accurate, up-to-date information about COVID-19 relevant to their project and country, so that they are not placing themselves or others at unnecessary risk when undertaking research?
  - b. How can the needs of individuals or groups with particular characteristics who risk being affected disproportionately by any changes made to research during this period be taken into account [see Box 2]?
  - c. Have research ethics and data integrity risk assessment and implementation plans been revised in relation to COVID-19?

# **Box 2: List of most vulnerable groups**

- Research with children and young people under 18.
- Research with vulnerable adults (defined as people who are 18+ and at greater risk of significant harm due to the intersection of factors including gender, age, disabilities (including psychological and learning difficulties), poverty, illness, ethnicity, or experience of crisis.
- Research on gender, women/genderbased violence, people with disabilities.
- Research with stigmatised groups: sex workers, people living with HIV/Aids, lesbian, gay, bisexual, transgender, queer (LGBTQ+) or third gender people.
- Research in contexts where there is ongoing violent conflict.
- Research on sensitive issues in contexts where the rule of law is weak.
- d. What support (financial and other) is being offered for enumerators who may be more exposed to exploitation as a result of financial uncertainties and / or do not have access to necessary equipment or infrastructure to continue their work?
- e. How are it be ensured that myths about transmission and infection do not influence research decisions or practice? What can be done to prevent and address increased racial harassment of enumerators/participants in relation to these myths?
- 4. Conflict sensitivity<sup>4</sup>: National and local responses to COVID-19 risks fuelling local conflict and community clashes and compromising the safety, security and dignity of research participants, local communities, and enumerators. This has the potential to impede project delivery and impact on the evidence required for programme learning and adaptation. With so much attention being put on health responses, other activities aimed at building social cohesion, creating spaces for dialogue, etc. are being suspended. This carries the risk of escalating tensions within communities to go unnoticed or to be disregarded to meet the urgency of the public health emergency.
  - a. What is the impact of COVID-19 on conflict and community tensions in the local area? Country teams should periodically update their update their conflict analyses throughout COVID-19.

<sup>&</sup>lt;sup>4</sup> The guidance has been adapted from: Bentele,U. (2020) *Guidelines to Conflict Sensitive Research*. Swiss Academy of Sciences (SCNAT). Available at: <a href="https://naturalsciences.ch/uuid/2f008d33-a633-5c9d-886b-f7b88195f84b?r=20200527115808\_1582122358\_9a6486cf-11b9-5546-9793-e15c3e5659b4">https://naturalsciences.ch/uuid/2f008d33-a633-5c9d-886b-f7b88195f84b?r=20200527115808\_1582122358\_9a6486cf-11b9-5546-9793-e15c3e5659b4</a>

- i. How can the impact of the research (positive and negative) be monitored to avoid negative impacts and unintended consequences?
- ii. What mechanisms are there in place to regularly update the conflict analysis and to make any necessary adjustment to the research?
- b. How does the impact of COVID-19 interact with the issues driving the conflict and/or the fragility of the community?
  - i. What interests do the different stakeholders have in any COVID-19 related research / data collection that is carried out? How are they positioned within the community? How might their response to COVID-19 and engagement with the research be perceived within the community?
  - ii. What impact will this have on research/data collection including access to participants, the locality, security and data quality and quantity?
- c. What is the position of the research participants within the community?
  - i. Are there 'new' or increased risks to the research participants as a result of COVID-19?
  - ii. How will their participation in the research be perceived by the surrounding community?
  - iii. Will the research raise expectations of research participants and their respective communities (e.g. through humanitarian assistance)? How will this be managed and communicated in a way that is clear and transparent?
  - iv. How accessible are the research participants? (Consider the geographic location as well as the cultural and security environment). Is there enough flexibility in the research design to allow for alternative types of data collection, such as remote methods of data collection? How might this impact on the quality and quantity of the data?
- 5. Integrity and transparency: COVID-19 risks impacting on the way we work and the actual work we can carry out.
  - a. How are different country contexts in relation to the timing and impact of COVID-19 being considered so that realistic research activities are implemented? Is the research design sensitive to the context and local values?
  - b. Are partners being consulted on the potential impact of COVID-19 and the risks it poses to communities where work is being funded? Are the voices of those who are most affected by COVID-19 meaningfully included in deciding what research takes place, where, and how? How are you promoting fair and equitable research collaborations between partners in high- and low-income settings?
  - c. How are modified research plans (and the potential financial implications) being communicated?
  - d. How can research be modified to reduce the risks of transmissions for those involved in the research and comply with country 'lockdown' regulations. What advice and support is being offered? (see Lutpon 2020 for a comprehensive compilation of online research methods<sup>5</sup>).
  - e. With more data collection taking place remotely, how can participation and engagement of (already) marginalised groups who may struggle to access and use

<sup>&</sup>lt;sup>5</sup> Lupton, D. (editor) (2020) *Doing fieldwork in a pandemic* (crowd-sourced document). Available at: https://docs.google.com/document/d/1clGjGABB2h2qbduTgfqribHmog9B6P0NvMgVuiHZCl8/edit?ts=5e88ae0a#

- digital tools be ensured (including persons with disability and persons with low literacy)?
- f. With more data collection methods taking place online and using remote methods with often less secure networks or software, how can participants data and confidentiality be protected? What additional responsible data management measures need to be implemented?
- g. Can remote data collection methods even if rapidly and light touch be piloted to seek feedback from researchers and participants? Has consideration to the time it takes for the data to be collected online? Keep surveys and questions short to minimise the time needed for a participant to access a device (phone, internet).
- h. Do enumerators have the right skills for remote data collection? All the skills which enumerators need for data collection are even more important when remote methods are being used. For example, enumerators will need strong communication skills in order to develop rapport with participants and put them at ease.
- i. Do enumerators have skills needed to detect distress in participants, even when they cannot see them? Enumerators will need to be even more alert to participants' reactions during the data collection process so they can judge when data collection may need to be paused or stopped, and know when/how to safely signpost participants to support services, where needed (e.g. through SMS text messaging services). This will be all the more important given increased levels of domestic violence triggered by lockdown measures.
- j. How are the expectations of research participants being managed? The remit, purpose what participants can expect from the research should be transparent and clearly communicated.

Protocols for collecting participant information from partner organisations, that are GDPR compliant:

For partners to be able to share participant contact details:

- 1. Partners should be provided with information about the project that they can share with the contact base. This should include information about:
  - Who we are
  - What the project is about
  - Why we are collecting the information, and why at this time during COVID-19 (including that this is to reduce the risk of spreading the virus)
  - Why we want to contact the participants
  - What information we require (i.e. only get the personal information we need to contact potential participants (e.g. name and phone number)
  - What ethical and safety protocols will be followed to minimise putting participants and researchers at harm.

It is important to be transparent and clear about what is going to be done with the information.

- 2. Partners can send out a general notification to their database (using whatever means they would normally do so (e.g. SMS, email). In other words, they do not have to contact their database on an individual basis.
  - Under a 'legitimate interest' clause, partners do not have to require people
    to opt-in but they should offer their contacts an opportunity to object / optout of the process. A deadline for doing this could be considered. A
    legitimate interest form needs to be completed and signed off by ECID.
- 3. If carrying out interviews with vulnerable and/or marginalised group, consideration should be given to using pseudonyms rather names prior to partners sharing the information with ECID staff.
- 4. All spreadsheets (or other electronic documents) that contain personal information should be password protected and adhere to strict responsible data guidelines.

# Protocols for phone interviews, that are GDPR compliant:

- 1. ECID consortium members should issue enumerators with work phones (i.e. Personal phone numbers should never be used or shared).
- 2. The phone call should begin by asking the person if they are happy to be contacted and to take part in this research / interview. If no, hang up.
- 3. If yes, information about the interview should be read to the person. Ask if the person agrees to continue with the interview. If yes, agree on a suitable time / date to contact them (see Appendix 1). This should include details about:
  - The information that is being collected, why and how it is being collected, and how the information will be used.
  - The ethical and safeguarding procedures and protocols.
  - It should also state that the information will be stored securely and not held any longer than required for use.
  - It is important to state that their participation will have no impact on their access to services. Answer any questions or address any concerns the potential participant may have.
  - 5. At the time of the interview, an agreed consent statement should be read to the participant (Appendix 2). Ask the participant if they are in a safe space to proceed with the interview.
  - 6. If the calls are recorded, participants need to be informed and given the reason for this.
  - 7. Consent needs to include a tick box statement that records that this person consented to use their personal information for this purpose on this date by this method. Once verbal consent has been received, the enumerator can tick the tick box
  - 8. A record of this consent should be securely kept.
  - 9. Ensure that the enumerator has information to hand on the referrals / services including those related to COVID-19 to share with participants.
  - 10. Enumerators should be trained to identify distress over the phone, and to react in accordance with suggested protocols if this is the case e.g. to terminate the call or signpost the participant to relevant services and resources.

# Protocol for doing face-to-face interviews during COVID-19:

# Face-to-face interviews should only be carried out if:

- Community leaders should be consulted to ensure acceptance around inperson or remote engagements and any related measures to promote safety
- It complies with local COVID-19 regulations
- A revised risk assessment which considers the risk (to researchers/enumerator and participants) related to COVID-19 is carried out. This risk assessment should include, at least:
  - Risk of spreading the disease
  - Risk for the enumerator and for the participants in the data collection process
  - Reputational risk for the organisation
  - Safeguarding risks due to increased vulnerability of participants, especially women and girls and persons with disability.
- It is feasible and necessary to conduct face to face interviews. No alternative options exist for carrying out interviews remotely.
- Enumerators are trained on the different aspects of the ethics protocol for carrying out research during COVID-19.
- CA staff, partner staff or volunteers who more vulnerable to severe illness
  due to COVID-19 should not participate in face-to-face interviews. Those
  who are experiencing symptoms of COVID-19 should not participate in
  face-to-face interviews and should self-isolate as per WHO guidelines

**Note**: Timescales for the lifting of restrictions are not currently clear and just because a host government has reduced the restrictions, it doesn't mean we should see that as green light to carry out face-to-face interviews. Aside from doing no harm, there are obvious reputational risks if we visit a community and they link any rise in cases to our presence.

# How to carry out face-to-face interviews when the time is right:

- 1. Avoid sending anyone into a community who doesn't already live there.
- 2. All staff and volunteers representing Christian Aid or a Partner organisation who are undertaking face-to-face interviews should carry identification documents and copy of any documents authorising access to the community.
- 3. Avoid close contact with people. Country social-distancing rules should be adhered to
- 4. On the day of the interview, an ECID staff member (from CA, partner or enumerator) known to the community should make contact to:
  - Confirm that all parties involved are able to attend and not required to selfisolate for any reason.
  - Confirm what language participants are comfortable using.
  - Clarify if participants need support with translation or if they need any other support to help them participate in the interview.
- 5. If the individual that is going to be interviewed or a member of their household has symptoms, then the interview should be postponed. If this is the case, a list of referrals (including COVID-19 services) should be shared with the person being interviewed.
- 6. If the enumerator/ or a member of their household has symptoms of COVID-19, the interview should be postponed
- 7. If there is concern on the day of the interview that an individual is displaying symptoms not previously reported then the interview should postpone or halted.

### > In the instance that the interview can be conducted:

- 1. Enumerators must wear a mask at all times. Appropriate training must be provided.
- 2. When the interview starts, the enumerator must explain to the respondent why they are wearing masks.
- 3. Country programmes should decide if it is appropriate to give PPE to respondents. If yes, do not hand the PPE directly to the person, put them in a safe space for them to take and use. Hand sanitiser should be used before touching any PPE is that shared.
- 4. Only use non-physical contact methods of greeting and thanking people (i.e. No handshaking)
- 5. Ban sharing of food and drinks— no biscuits, communal plates of foods or drinks should be shared.
- 6. Ensure the physical distancing and hygiene (coughs and sneezes etc) guidelines are shared with the interview participants in their native language prior to the interview
- 7. If moving chairs around for the interview, make sure to use hand sanitiser before and after. Use a 0.05% chlorine solution for handwashing if soap is not available.
- 8. Create a physical safe space. If possible, conduct the interview in outdoor open spaces. The space needs to be private to allow the respondent to speak openly and frankly during the interview.
- 9. If the interview is being carried out indoors try to meet in large, ventilated rooms even if there are only a few people. Switch off any air-conditioning; ventilate by opening windows and doors.
- 10. Disinfect surfaces doorknobs and handles, tables, chairs, desks, handrails, hardware and any other surface you may need to touch should be wiped down using a 0.5% Chlorine solution.
- 11. Ensure that hand washing facilities are available before entering the interview room.
- 12. Anyone involved in the interview (enumerator, participant and translator) should be seated at least 2 metres apart (or in line with local social distancing regulations.
- 13. Provide a pull-out tissue box for interview participants
- 14. Avoiding touching your eyes, nose, and mouth
- 15. Cover any personal coughs or sneezes with a tissue or a bent elbow, then throw the tissue in a bin and wash your hands.
- 16. Ensure that frequently touched surfaces are cleaned before and between interviews and at the end of the day including any communication aids used.
- 17. Sanitise hands before and after every interview with an alcohol-based hand rub if available and if your hands are not visibly dirty or with soap and water if hands are dirty.
- > See link for printing and additional resources on mixing chlorine solutions <u>here.</u>
- All standard procedures for conducting Key Informant Interviews should be followed. This includes:
  - Obtaining informed consent.
  - Following CA safeguarding procedures.
  - Stopping interviews if someone shows signs of distress.
  - Providing the enumerator with a list of available referral services to share with the participants.
  - o Providing a feedback and complaints mechanism.
- Country teams will have additional measures for their context that they should also implement.

# Appendix 1: Information required for gaining consent in phone interviews

Note: This is a script for the enumerator to use when speaking to the participant.

- 1. Ask the respondent if they received the information about the ECID programme from the partner organisation and if they are happy to take part in an interview.
  - a. If no, thank the person and hang up.
  - b. If yes, ask the participant if you can tell them about the project and how you would like them to be involved.

#### 2. WHO WE ARE

Evidence and Collaboration for Inclusive Development (ECID) is a project operating in Myanmar, Nigeria and Zimbabwe. The purpose is to collect data about people's experiences of marginalisation with the aim of improving access and quality of service provision with communities, government and service providers. The project is led by Christian Aid and funded by the UK Government through UK Aid.

## 3. WHAT WE ARE DOING

Country programmes should insert the following information:

- i. The purpose of the research and/or data collection
- ii. Why this research / data collection is important and the difference it hopes to make.
- iii. How the data will be used.

### 4. WHY YOU'VE BEEN SELECTED

In this study we are interviewing people who have experience of accessing different community services.

Country programmes should insert:

- 1. A sentence about why a person has been selected for the interview e.g. You have been selected to study because of your previous engagement with [name of partner organisation].
- 2. A sentence about who will be interviewing them (e.g. male / female)

Participation in this study is voluntary, and you can withdraw yourself at any time without consequences. Participation in the study will have no impact on your access to services, including access to COVID-19 services. If you anticipate any issues arising from participating in the study, please let us know.

# 5. WHAT ARE THE NEXT STEPS

Due to COVID-19 and to avoid transmitting the virus, we are interviewing people over the phone. If you decide to take part, the interview will be recorded for later use.

Before continuing there are a few things you should be aware of:

1. We can either carry out the interview now or find a time that suits you. The interview will be no longer than 30 minutes.

- 2. Please make sure you are in a safe and private place for the interview, if possible. If you need someone to translate the interview, or if you need any other support to help you participate in the interview, please let us know in advance.
- 3. The interview will be conducted in [state the language] unless otherwise requested.
- 4. You will be asked for your name and phone number. Your personal information will be treated confidentially and anonymously unless we believe you or someone you know is at risk and we have a legal obligation to report it. You will be assigned a code or pseudonym to ensure anonymity which will be used for any documentation referring to our discussion.
- 5. You will also be asked for your verbal consent over the phone at the time of your interview. This will include the interviewer asking you some questions. You can also choose to withdraw from the interview at any time.
- 6. You have the right to request access to the personal information you shared. This is a formal process, which once requested, would trigger or Subject Access Request process.
- 7. We will provide you with feedback to let you know how your data has been used and to ensure your views have been properly represented.
- 8. Your information will be stored securely and not held any longer than required for use.
- 9. On completion of the project, the electronic recording will be permanently deleted.

### 6. WHAT CAN YOU EXPECT FROM US

All individuals involved in the study shall be treated equally, irrespective of race, ethnicity, gender, religion/or none, sexual orientation, profession, lifestyle (for example sex work, drug use), marital status, age, community background or disability. No one will be judged or discriminated against on the basis of any aspect of their identity.

If you feel any adverse / negative effects as a result of participating in this interview you should report it immediately. This might include feeling bullied or harassed, unhappy about the conduct of the person interviewing you, or simply feeling more at risk as result of participating in the interview.

## Country programmes should:

- 1. Include a statement about safeguarding and how they can make a complaint or raise an issue if the need arises.
- 2. Give the participant a list of referrals/services including COVID-19 services.

We will not be able to pay you in any way for taking part in the study, but there are other benefits to participating.

Countries programmes to include 1-2 sentences on the benefits of participating in the study.

# **Contact details**

We understand that you might change your mind in the future. You can contact us at any time if you want to withdraw from the project, if you there is any information you do not want us to use, or have any questions or complaints about your participation in the project.

- Contact name:
- Contact email:
- Contact phone number:

Do you have any questions and are you happy to continue with the interview (either now or at time that will suit you better)?

If yes, then on the day of the interview read the statement in the consent form (see Appendix 2).

# Appendix 2: Consent form for conducting interviews over the telephone.

Note: This consent form should only be used once the person has been given the relevant information about the interview. If the person has given verbal consent to continue with the interview, then read the following statements and tick relevant box

Consent questions	Yes	No
I confirm that I have been given and understood the information		
provided for the above study and have asked and received		
answers to any questions raised.		
I understand that my participation is voluntary and that I am free		
to withdraw at any time without giving a reason and without my		
rights being affected in any way.		
I understand that ECID will hold all information and data collected		
securely and in confidence and that all efforts will be made to		
ensure that I cannot be identified as a participant in the study		
(except as might be required by law) and I give permission for the		
researchers to hold relevant personal data.		
I agree to take part in the above study.		
I agree to the interview being digitally voice recorded.		
I agree to the use of my words in publications without mention of my name.		
I agree that my information used in the study may be stored		
(without my name(s)) electronically, until the programme has		
been completed and the information is no longer required.		
PLEASE TICK.		
I, (name of field researcher / enumerator)		
declare that I have accurately represented and recorded the consent	of the par	, ticipant.
addiction that it have additionally represented and recorded the comboni	o. and par	

been completed and the information is no longer required.		
PLEASE TICK. I, (name of field researcher / enumerator)  declare that I have accurately represented and recorded the consent	of the par	ticipant.
Date:		